Forrester-Jones, R. (2021) Older carers of people with learning disabilities: their experiences with local authority assessment processes and personnel. ***Tizard Learning Disability Review***

Abstract

Purpose - Amongst other actions the Care Act 2014 emphasised the duties of local authorities to assess the needs of carers as well as those they care for, and to meet all eligible needs for support. This paper aims to report the findings of a study which explored the experiences of older carers of people with learning disabilities as they navigated local authority assessment processes and personnel.

Design/methodology/approach - Using an explorative design, 21 older carers were interviewed about their experiences. Interview transcripts were qualitatively analysed.

Findings - Three main themes were identified: needs assessments as ambitions not outcomes; the effects of funding-cuts projected onto carers; and challenges with social care personnel.

Originality/value - The study findings attracted a high level of engagement with public awareness and mainstream news and social media. The local authority also immediately responded with interventions to address some of the findings, including carer 'drop-in' sessions. They are also adapting their carer's needs assessment processes as a result of the study. It is hoped that the issues raised will be of interest to other social care providers and practitioners.

Introduction

The UK Care Act 2014 (CA) placed new duties on local authorities (LAs) to assess and meet the eligible needs of people with disabilities and their carers. Yet, since the Act came into effect in 2015, the experiences of older (65+years) carers of people with learning disabilities (LD) have not featured appreciably in the research literature. Rather, the majority of studies have investigated the experiences of young or working informal carers or carers supporting people with dementia and mental health problems, Larkin *et al*. (2019, p.55) stating "far less is known about older carers or caring for someone with multiple needs". Mahon *et al*.'s (2019) scoping review of research specific to older carers of individuals with LD found only six UK based studies, the most recent being Pryce *et al*. (2017). Mahon *et al*. lamented the limited availability of research and how the majority of LD carer specific studies focused on the general theme of planning to meet future care needs (also reiterated in Walker and Hutchinson's (2018) systematic review of qualitative studies) with less attention paid to carers' daily experiences and needs. Most recently, Gant and Bates (2019) explored how older parents of sons/daughters with LD responded to the CA. Whilst their participants were 'cautiously optimistic' about the Act's likely implications, they remained unclear as to its relevance for their adult child's life and their own wellbeing. However, similar to other post-2015 studies, the sample in this study (*n*=5) was very small, limiting the scope of the findings.

The study reported here, which took place in 2019, aimed to redress some of the limitations of previous studies by interviewing a larger number and wider range of family carers than just parents, and exploring what caring meant to their day-to-day lives. The objective was to help inform the commissioning charity, New Forest

Mencap (NFM), regarding their plans to support older carers as well as people with LD. An allied paper (Forrester-Jones, 2021) describes how the study sample perceived their day-to-day caring role as resembling that of a care manager, due to the range and complexity of the tasks they performed. Yet, unlike a paid care manager, their role continued with little respite into the retirement phase of their lives. Their anxieties about what might happen to their loved ones* once their own capacity to care had diminished or after they had died was also a significant theme. The current paper focusses on three additional areas discussed by carers – their views about the needs assessment process, their perceptions that austerity cuts were being projected onto themselves by services, and their experiences of service personnel. This paper is an abridged version of the original report (Forrester-Jones, 2019a).

Method

Methodological and ethical details of the study are described in detail in Forrester-Jones (2021) but briefly re-stated here. I interviewed 21 older family carers using a range of structured open-ended questions with prompts that were initially co-produced with NFM. These questions were then re-ordered, added to and reassigned as each interview progressed. This iterative approach allowed for expansive themes to emerge from the data.

Recruitment

The sample were recruited from a semi-rural area of South East England via adverts calling for family carers who were 65+yrs and caring for their adult family member/s

with LD. The adverts were placed in local newspapers and the e-newsletters of the Clinical Commissioning Group (CCG) and NFM.

Ethical considerations

A favourable ethical opinion was received by a university research ethics committee (REF: 280818/SSREC S19-056). All of the study participants had capacity to consent. Information sheets were provided and signed consent forms returned. Confidentiality, anonymity and voluntariness were emphasized to each participant before and during the study. The final report was made available via hard copy and electronically in portable document format (pdf) to all participants and an accessible summary as well as the full report were placed on the NFM website and the University portal.

Analysis

Interpretative Phenomenological Analysis (Smith and Flowers, 2009) entailed line-by-line coding of transcribed interviews (using NVivo 12 software). This enabled recurring patterns of meaning (thoughts and feelings) to became subthemes which were then grouped together into main themes illustrated by substantive quotes (with pseudonyms and numerical codes to maintain anonymity).

Findings

Sample characteristics

The sample consisted of 21 older (65+ years) family carers (5 of whom were males). In 5 of the interviews 2 carers (partners) were present. Six of the 11 other participants were single carers. The average age of the 18 participants who volunteered their ages

was 75 and 20% were aged 80 years or above. The average age of the carers' family members with LD (*n*=16) was 45 years. Eight were living at home with their families and eight in supported-living arrangements with paid support. All were in receipt of local authority personal budgets with twelve receiving Direct Payments. All but one were getting some level of social care such as support for domestic tasks or day care activities.

Interviews

Theme one: needs assessments and carer assessments as ambitions not outcomes.

All of the participants reported difficulties with the assessment process both for their loved ones and for themselves.

Subtheme one: unsatisfactory needs assessment process

None of the participants reported being satisfied with the needs assessment process. Some reported that, despite their substantial caring role, they felt excluded when needs assessments took place, catching sight of their family member's care plan only after its completion. It was also a frustration when assessors didn't use accessible communication styles; rendering the written paperwork useless (and arguably invalid) for the recipient who could not read/understand it:

> *Cynthia told us she was due to have an assessment –we weren't involved…and she can't read and she sends it to us. But under the Data Protection Act, they send it all to her, but she can't read. (012)*

Under the CA, assessments should involve all relevant carers including family members – who should be asked about the person's needs if the person has

‘substantial difficulty’ in participating in their own assessment. Yet this did not appear to be the experience of some family carers in this study.

Two participants stated that their loved one had been ‘diagnosed’ with challenging behaviour, but 11 others also described behaviour that increasingly challenged them, especially as they themselves grew older and frailer. Yet despite the wealth of evidence supporting the positive effects of functional assessments and positive behaviour support plans on the wellbeing of both the cared-for and the carer (e.g., Baker and Osgood, 2019), and stipulations for such assessments, if appropriate, under the CA (Forrester-Jones, 2019b) none of the participants in this study could recall having been offered a functional assessment.

Subtheme two: getting needs assessment reviews proves difficult

As people with LD age, their need for social care often increases. Yet carers in this study reported how their efforts to get needs assessment reviews for their relatives were often frustrated. For example, one 80-year-old single parent and sole carer recounted how, after moving to a new region the previous year, a needs assessment transfer from the previous LA for their loved one had not happened. Waiting times and assessment delays appeared to be beyond the ‘reasonable time-frame’ (four to six weeks) from requests to LAs (s6.29 Care and Support Statutory Guidance 2020).

> F: well she was supposed to be reviewing it and I’m 99% certain that her sole intention of coming round was to say ‘nothing’s changed he doesn’t deserve anything more’. (020)

Subtheme three: care plans as rhetorical rather than real

Participants also shared how not all of the support specified in care plans I materialised (despite the LA duty to provide for eligible needs); therefore perceiving the outcomes of the needs assessment process as more rhetorical than real:

> *Bryn had a Care Assessment – nothing came out of that. (016)*

> *[…] so if I look at the care plan […] which is almost non-existent actually because we have lots of things on the care plan - none of them fulfilled - but if I look at the care plan it is an ambition, it is not a care plan. (005)*

Subtheme four: carers' assessments result in few outcomes

A similar story emerged for participants who had requested a carer's assessment. Either they did not receive one:

> *It took five months to get a social worker then to start the process. Then the social worker went silent – no carer's assessment […]. (011)*

Or it had not resulted in any support:

> *I did a carer's assessment about a year ago but we never get anything because we don't have any continuity now. I just never heard from them and we've never [had] a visit since. And my husband needs it more now because although I am the main carer he is* [also caring]. *(005)*

> *I am his* [relative with LD] *sole carer. I had a carer's assessment a couple of years ago. [But] I just do everything around him. I am 71 but I feel 90 some days. (003)*

She [assessor] was supposed to be doing my carer's review […] and after the first two questions she said "oh nothing's changed". I wouldn't say that was a review - it was just "oh I can't be arsed with this." I don't get anything [support].(020)

Theme two: challenges with social workers and other service personnel

All of the participants described how their experiences of 'battling' with social care services had become more intense and routine over the last few years. Particular issues that were important to carers included the absence of a consistent social worker to deal with their loved one's case, as well as a perceived lack of professional expertise in LD.

Subtheme one: difficulties with 'getting' a social worker or being allocated an 'absent one'

Around two-thirds of the sample reported that their loved one had been allocated a social worker with the remaining third stating that they wanted one, but had not been allocated one:

I did get in touch with Social Services…I told them about Josh when we moved here and asked how I would go about getting a social worker…and if Josh could be put into the system if anything happened to me. But I didn't get any reply. Nothing. (015)

The absence of a social worker (even when one had been allocated) led some carers to adopt innovative measures to attract attention from social services:

We […] have an allocated social worker. It's just that we never see them - we haven't seen our social worker for two years. The only contact I have with social services now is when they ask how much money I can give back because they know I can't spend it. So how immoral is that? They give me a care package but they won't allow me to spend it on anything other than day-services and there aren't any day-services. And in order to get social services interested in Cindy and she's, you know, critical on every score – so every so often I phone up or email and say, "You need to come and see us because there is money to give back". (005)

Whilst the study sample appreciated the need to work with professionals and were motivated to do so, the quote above exemplifies how, similar to the findings of Gant and Bates (2019), lack of social worker input meant that family-professional partnership working was not always realised.

Subtheme two: lack of continuity of social workers

Even when a social worker had been allocated, participants reported that a workable relationship between the social worker and their loved one was not easily established due to the lack of continuity in personnel:

[…] the thing with social services that we just don't seem to get past…is we have a social worker but not a permanent one, you know they just seem to allocate different ones. (009)

Frequent changes of named social workers added to carers' 'task' burdens including having to repeatedly narrate their loved one's needs to each new social worker:

[Every time] I am expected to type things for social workers – they [social workers] change all the time. (016)

The lack of continuity of social workers appeared to be most problematic in times of crisis. This is exemplified by a carer who recounted how, instead of gaining professional support following a family bereavement, their loved one experienced instability of social worker input:

At the time of the tragedy Juliette was given a short term social worker who [said] "Oh I will only be Juliette's social worker until we find her somewhere to live." It is almost as if, you know, 'the case is closed'. (007)

In the situation described above, the person with a learning disability appeared to miss out on professional support at a time when they most needed it. Whilst the death of a family member is generally emotionally difficult for anyone, for a person with a learning disability it can result in additional losses of support including their accommodation. A lack of speedy bereavement support can lead to confusion and clinical depression which may also result in challenging behaviour (Forrester-Jones and Broadhurst, 2007).

Long stretches of time characterised by fleeting professional support (Gant and Bates, 2019) or a rapid turnaround of turnstile of social workers can lead to negative impacts for the carer who is left to deal with the outcome as well as for the person with a learning disability:

[...] umm social workers come and go […] and of course life happens but nothing is standing still for my Cindy and it makes for a very scary world for her.

[And] Cindy [has] challenging behaviour, partly because she doesn't understand the complexity of the world. (005)

Carers' vexations of what appeared to be structural short-termism described above are also shared by social workers themselves, with commentators such as Ferguson (2012) and Pearson and Ridley (2017) calling for a radical transformation of current social care models.

Subtheme three: the effects of funding cuts projected onto carers

Participants also talked about how social workers gave the impression that the amount of support (if any) was reduced as a result of government funding cuts and how delay measures (e.g. utilising 'lists') inadvertently served to dissuade carers from applying for support. Family carers also felt that this 'funding crisis' implied that they should shoulder the burden of care with little support – which appeared to create a social milieu of 'us (family carers) and them (social workers)':

They said "you are not getting enough care but saying this, we can't afford it". The social worker said they would put Tom on a waiting list. (018)

Well she [social worker] *was supposed to be reviewing it* [care plan] *and I'm 99% certain that her sole intention of coming round was to say "nothing's changed he doesn't deserve anything more".* (020)

Everything boils down to the fact that they [LA] *are in a funding crisis and […] they are putting up the barriers. They are not there to help you. They pull up the draw-bridge because we have now become the enemy at the gate […] I mean this is government policy you know. (009)*

Subtheme four: perceived lack of social worker, assessor, and 'gatekeeper' expertise

Some carers felt that they were not generally provided with information about support that might be available (a stipulation in the CA). For others, repeatedly being given the same information about support that might be available - when what the carer really wanted and needed was tangible help to access it - implied a level of incompetence:

> *You know it amazes me because every time the social worker comes, they say to me "Oh are you part of the Prince's Trust?" and they pass me a piece of paper about it and I say "Yeh I know this much about it because every time you come, you give me one of these [leaflets] and I don't have time to get involved in it." And yes…I'm sure there are lots of things out there that I would like to know, but I just need help to do them and what I will get annoyed about is if you just tell me "do this, do that, do the other." (020)*

Many participants also perceived LA staff, including 'service-gatekeepers', to be lacking in a requisite level of skill and expertise in learning disabilities which did not help with their overall confidence in service personnel:

> *I had someone on the phone once and umm…when I had complained about the lack of support we were getting, she said "Oh, when did Juliette catch Down's Syndrome?" I don't know... I was on the phone and I don't know if she was in some sort of call-centre which had been out-sourced because when you go on the website of [LA] you just get their phone number and that is definitely a call-centre. (007)*

You know the last time I had a social worker round trying to get more support [for loved one] *the first thing she said was "well he gets nearly 3 hours support a day already". Well it isn't three hours a day because 14* [hours of support per week] *into 7 doesn't go 3 times, or 7 into 14 doesn't go 3 times!*

Interviewer: so what did you say to her when she said that?

To be honest I can't remember. I was so gobsmacked and so annoyed with everything she said, so […] umm we left it. (020)

She [social worker] wasn't particularly good. I must admit I did complain as she did some very naughty things in as much as she never took any notes and nothing was ever put on file. (007)

For family carers who were experts-by-experience by virtue of having spent almost a lifetime caring and battling services for their sibling, child or relative, such 'mistakes' and 'faux pas' as illustrated above were hard to take, especially when they felt they were being 'put down' by social workers:

Social workers have been patronising to me. I am very capable and competent. (016)

Patronising or pathologizing of family carers by social services is not extraordinary (Grey et al., 2015), and it is unsurprising that, once broken, the psychological contract between family members and social services is difficult to repair, family carers perceiving LAs to be disinterested in the long-term well-being of either themselves or their loved ones.

Discussion

The self-selected study sample was non-diverse especially in relation to ethnicity (a reflection of the study location). A study that looks at older carers through an intersectional lens – that targets categories including BAME, males, LGBTQ and physical disabilities would be useful to expand the scope for generalising the findings.

Whilst the proportion of older adult carers of people with learning disabilities is rapidly growing, research that specifically considers their needs has been slow to catch up. Perhaps more significantly, this paper shows that some of the aims of the CA, e.g. for LAs to undertake comprehensive needs assessments as well as carers' assessments, or implementation of support where needs are identified, are yet to be fulfilled, at least for this study sample. A way of organising social care that fosters social worker-family rapport and trust is needed to enable meaningful co-production of care plans, as well as dispelling confusion over eligibility (Seddon *et al*., 2007, p.1335). In order for this to happen, services need to give greater appreciation to older carers as experts-by-experience (Grant and Ramcharan, 2001).

Unusually, dissemination of the study findings led to immediate impact. Both NFM and the LA reported working more closely to jointly develop mechanisms to help monitor carers' wellbeing. Using their guidance for social workers, *'How to Support Older Carers of People with Learning Disabilities',* the LA also worked with NFM to improve the accessibility of information/advice to carers. Regarding the lack of carers' assessments identified in the study, the LA stated that they were monitoring assessment numbers and reporting them to a newly formed Carers Partnership

Board that they hoped the study sample would join. The LA stated: "*we remain committed to take the more constructive findings of this report and work in partnership with NFM and carers to form a strategic action plan to comprehensively address issues identified*." Promises by the LA to provide more ongoing support to carers within the local area, and to look at social worker continuity, were also made at the launch of the study findings, which included a panel of representatives from the LA, Mencap, the Down's Syndrome Association, and the local NHS Trust. The charity's subsequent influence on LA local decision making followed much mainstream and social media reporting of the study findings, confirming De Bruycker's (2019) suggestion that advocacy groups can benefit in their goals by appealing to the public's interest in media debates.

Of course, the problems identified in this study go beyond this single LA. The way that policy, funding and practice play out at a local level is significantly determined by and subject to national government strategies. Austerity budget cuts have left most LAs in England struggling to cope with rising unmet social care needs in a market that has steadily experienced lower recruitment and retention of social workers. The loss of workers through Brexit has fed into this fragile adult social care market (see Forrester-Jones *et al*., 2020 who interviewed 150 people with learning disabilities about the impact of service cuts on their lives, finding that individuals had become more reliant on family support following the loss of funded support or care hours). More studies that hear the voices of people with learning disabilities who are cared for by *older* family members are needed, as well as studies that look at the interfaces between older family carers, those they care for and social workers.

Pressures placed on LAs to make social care funding cuts may well translate into a politics of representation and exclusion whereby various groups of people with disabilities and their carers with unmet social care needs are jostling for attention and priority. The extent to which older carers have more agency over other groups is questionable and worthy of study. How social workers - who seek to provide support in extremely difficult times - are supported in terms of learning disability training, supervision and workload also needs urgent exploration.

According to Norman Lamb MP, Care and Support Minister in the coalition government, the Care Act 2014 was one of the most significant pieces of social care legislation in the last 60 years, placing the principle of individual 'wellbeing' at its core, ensuring that the cared-for *and* the carer could shape their own care and support to help achieve their independence for longer (Lamb, 2014). This research has indicated that there is still a way to go before the aims of the Care Act are truly being realised for older carers, with COVID-19 only exacerbating structural, financial and support problems already in existence.

Notes

*The term "loved one" is used, as this appeared to reflect how participants felt and talked about their adult family members. This term was agreed by NFM and participants attending a feedback event.

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